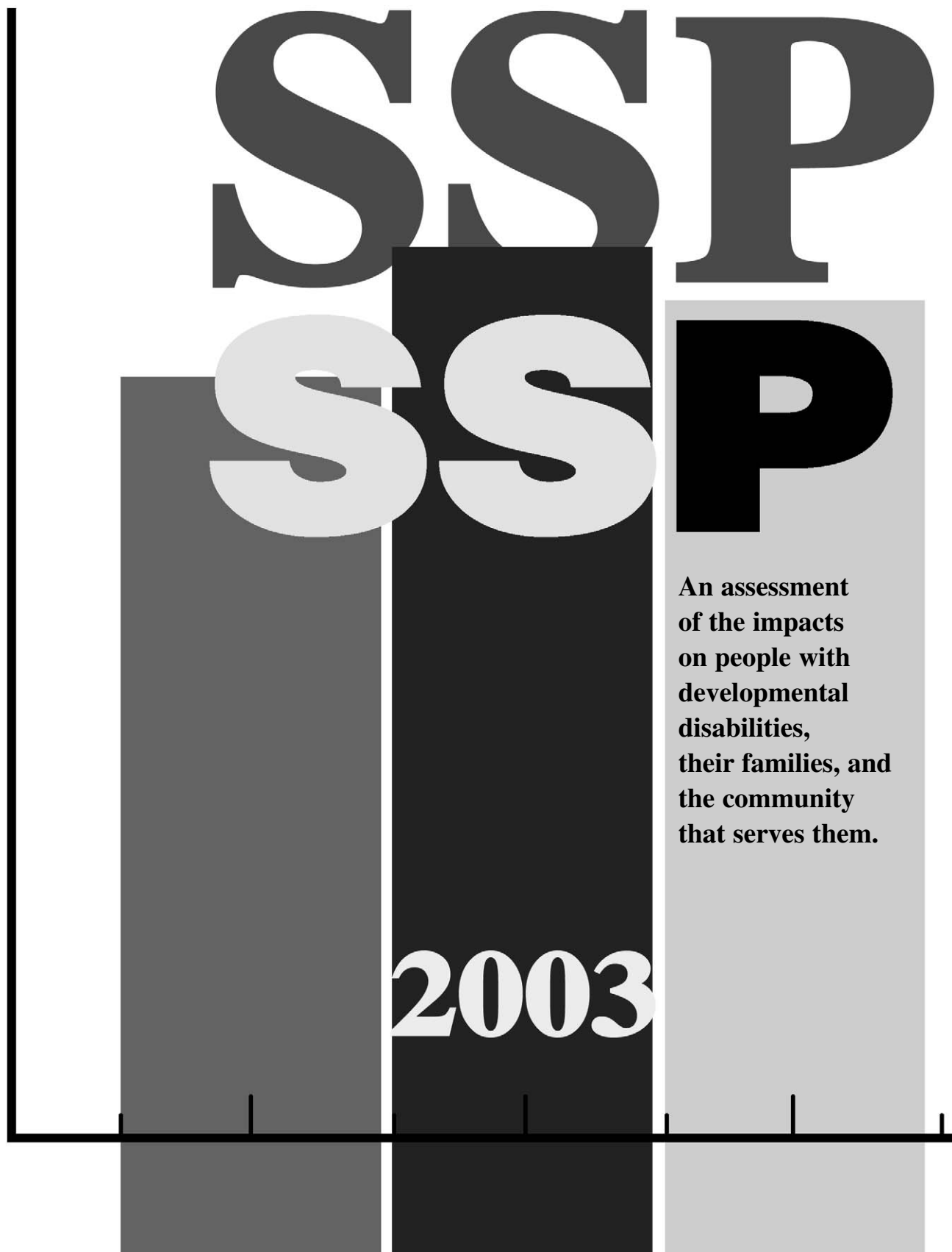


# ***Changes to the State Supplementary Payment***



# Changes to the State Supplementary Payment

*An assessment of the impacts on people with developmental disabilities, their families, and the community that serves them*

## 2003 Report

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# Acknowledgements

## SSP Project Advisory Committee

The SSP Project Advisory Committee provided oversight and review of this SSP research project and report development. The advisory committee consists of individuals with developmental disabilities, family members, service providers, and state agency staff.

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The Developmental Disabilities Council hired FLT Consulting, Inc. to evaluate the impacts of the SSP. Special recognition for the development of this report is given to the following members of the consultant research team.

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Staff from the DSHS Developmental Disabilities Division also provided data and technical assistance to the research team. Special acknowledgment is given to Linda Lunsford, SSP Program Manager; Lisa Weber, Senior Researcher; and Debby Davies, IS Applications Manager.

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## EXECUTIVE SUMMARY

This report is a first year assessment of the impacts of changes to the Washington State Supplementary Payment (SSP) on individuals with developmental disabilities, their families, and the community that serves them.

In 2002, the Washington State Legislature changed the method by which the SSP is issued to eligible recipients. As a result of legislative action [ESSB 6387], the original SSP is now distributed in the form of direct cash payments to specified persons supported by the Division of Developmental Disabilities (DDD) within the Department of Social and Health Services (DSHS).

After the 2002 changes, eligible recipients of three DDD programs received SSP cash grants in lieu of directly paid services. The three programs are:

### **Family Support Program**

Provides a variety of individual and community services to assist families in caring for their family member in their home. Respite care and therapies are included.

### **Residential/Voluntary Placement Programs (VPP)**

Provides a variety of residential services for eligible persons living with others or by themselves. VPP provides voluntary placement in foster care, under certain circumstances, for children under 18.

### **Employment/Day Programs**

Provides ongoing support services and training for eligible persons in preparation for employment, or for individuals with paid jobs in a variety of settings and work sites, which may include individual or group options in the community and specialized industry settings.

In 2003, the Social Security Administration (SSA) notified DSHS that specific SSP expenditures are disallowed per federal guidelines. This new interpretation will have further impacts in following years.

## **Research Methodology**

This report relies upon mail survey results gathered from 770 families and guardians of individuals with developmental disabilities. The survey data is supplemented by comments gathered through focus groups and an on-line questionnaire completed by individuals with developmental disabilities, families and guardians, service providers, state case managers, and county staff.

## **Findings**

The majority of families and guardian respondents:

- Like the SSP changes (65%)
- Perceive enhanced self-determination (65%)
- Are comfortable handling the SSP money (83%)
- Perceive either improvements or no change to their relationship with case managers/county staff and service providers

A majority of Employment/Day respondents (58%) don't like the SSP changes as much because:

- Increased burden
- Little to no added value

Case managers/county staff and service providers are concerned about:

- Accountability: how the money is being spent
- Fairness: who is getting it, and who is not
- Flexibility: how and when the money is distributed
- Communication: timely and accurate

Few people are losing eligibility for other benefits due to SSP changes. However, some people are falling through the cracks

## **Observations**

Based on the findings, several questions are highlighted for consideration by administrators and policy makers.

- Why are Employment/Day SSP-Recipients not as satisfied?
- Should SSP payments be more flexible?
- How can economic disincentives be eliminated?
- Should accountability and safety be improved?
- Can equity and fairness be improved?
- What lessons can be learned?

The report provides observations for each question as a starting point for discussion.

## **Conclusion**

Policy makers and technical professionals in the field of developmental disabilities should further analyze the results and findings from this first year assessment of the SSP.

In the fall of 2004, a second year assessment of the SSP will be published. This data will provide a longer-term analysis of the SSP impacts on individuals with developmental disabilities, their families, and the community that serves them. The 2004 report will also take into consideration the ongoing 2003 SSP changes mandated by federal requirements.

Based on the data and analysis of both 2003 and 2004 reports, a set of recommendations will be developed and presented to both DSHS and the 2005 Legislature to address the major points outlined in the reports.

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# INTRODUCTION

The Developmental Disabilities Council (DDC) hired an independent consulting firm, FLT Consulting, Inc., to evaluate the impact of the revised use of the State Supplementary Payment (SSP) on individuals with developmental disabilities, their families, as well as the community that serves them. The DDC is authorized by Public Law 106.402 to advocate for people with developmental disabilities.

This report is an assessment of the SSP changes in the intervening year after its revision by the Legislature.

## I. Background

In 1974, the U.S. Congress established the Supplemental Security Income (SSI) program to provide basic supports for individuals who have attained age 65, or are blind or disabled. Some states supplement the federal SSI payment with state-only dollars. In Washington State, the state-funded supplement to the SSI is the State Supplementary Payment (SSP).

As a budget reduction measure, the Washington State Legislature eliminated most of the traditional SSP of \$5-\$25 distributed to approximately 90,000 aged, blind or disabled individuals as a supplement to SSI. The state cut this funding from the general fund budget in 2002.

However, in order to continue to receive Title XIX Medicaid funding from the federal government, the state had to demonstrate maintenance of effort in the SSP from year to year. Consequently, the state identified services funded by state-only dollars that could be converted to SSP cash grants, requiring approximately 2,370 eligible individuals with developmental disabilities to pay directly for their own supports, rather than the state paying for these services on their behalf. A desired impact of this SSP change was to improve the self-determination of individuals with developmental disabilities.

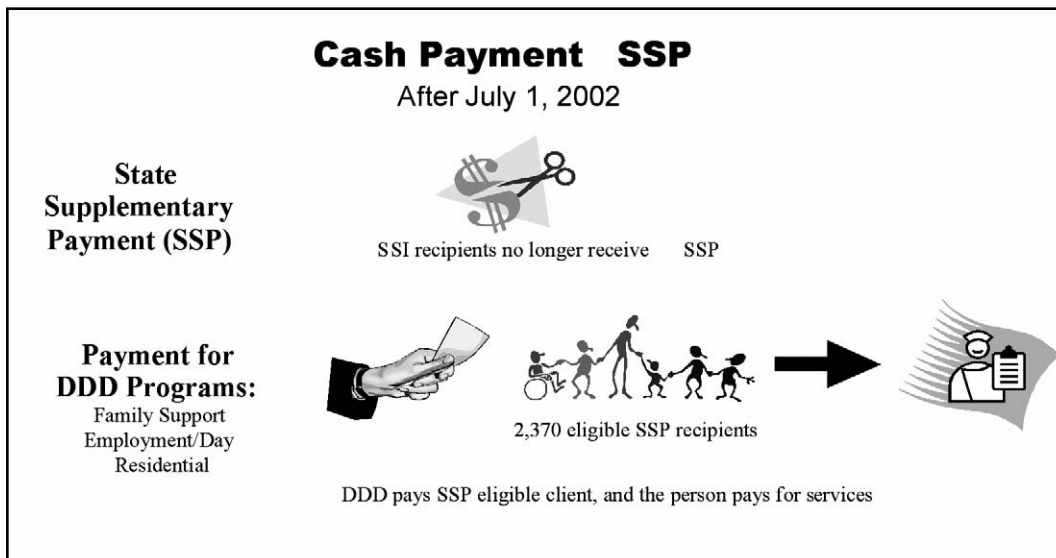
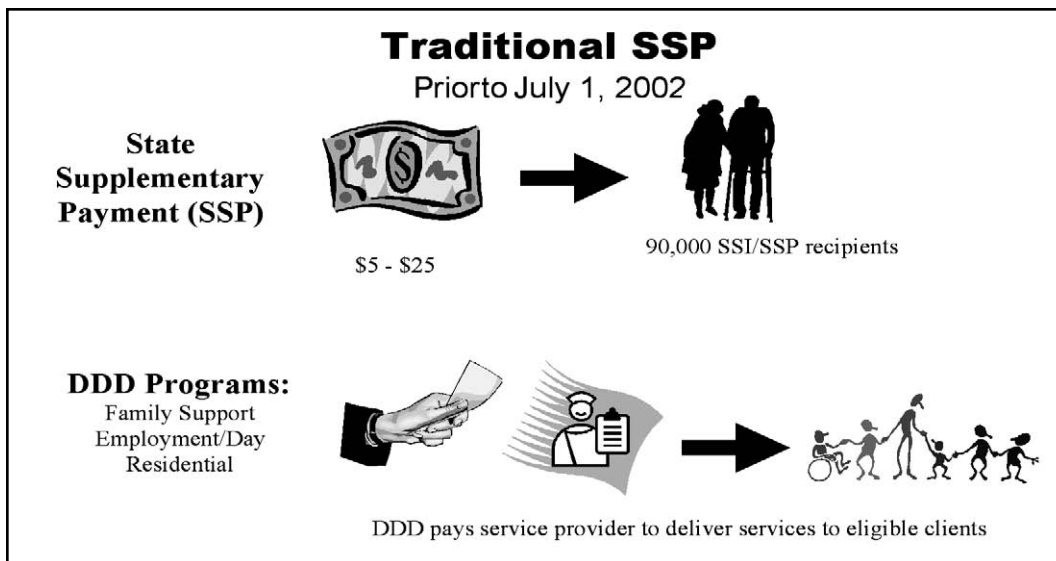
This study assesses the impacts on these individuals receiving direct cash SSP payments in lieu of directly paid services. It does not assess the impacts on the entire 90,000 population that no longer receive the traditional SSP payments.

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***“The legislature finds that providing cash assistance to individuals and families needing these supports promotes self-determination and independence.”***

*Washington State  
Legislature  
(ESSB 6387)*

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## II. Program Overview

After the SSP changes in 2002, some recipients of three Department of Social and Health Services (DSHS) Developmental Disability Division (DDD) programs received SSP to pay for services formerly funded with state-only dollars. The program dollars initially converted to SSP cash payments are: Family Support, Residential/Voluntary Placement Programs (VPP), and Employment/Day Programs. SSP is also issued to some previously unserved individuals who had need for family support or high school transition services.

In July 2003, the Social Security Administration (SSA) notified DSHS that certain SSP expenditures are disallowed. Changes as a result of this federal disallowance are the removal of restrictions on how the SSP is used for individuals receiving residential services and the complete removal of Employment/Day programs as SSP expenditures.

This federal ruling creates a shortfall in the maintenance of effort state spending level, which the Washington State Legislature will have to address in the 2003-05 supplemental budget.

## FAMILY SUPPORT

This program provides funding for a variety of individual and community services to assist families in caring for their family member in their home.

**Before SSP changes** - Individuals were awarded a specified amount of family support funds each year. The client could spend the funds on services provided by approved vendors, or for direct purchases (e.g. summer camp, wheelchair). The family was required to comply with state rules regarding the use of Family Support funds, use DDD contracted respite providers, and provide proof of purchase before being reimbursed for other expenses.

**After 2002 SSP changes** - All of the paperwork and mandatory compliances are eliminated for SSP funds. Funds are now disbursed directly to the client and spent as seen fit by the client, family, or representative payee.

**After 2003 Federal ruling** - Family Support Programs will experience no direct changes.

## RESIDENTIAL AND VOLUNTARY PLACEMENT PROGRAM (VPP)

These programs provide a variety of residential services for eligible persons living with others or by themselves. VPP provides voluntary placement in foster care, under certain circumstances, for children under the age of 18.

**Before the SSP change** - DDD reimbursed providers for services provided to clients.

**After 2002 SSP changes** - The individual, or representative payee, receives a check and pays the vendor directly.

**After 2003 Federal ruling** - Restrictions on SSP expenditures for individuals receiving residential and VPP Services have been removed.

## EMPLOYMENT/DAY PROGRAMS

These programs provide ongoing support services and training for eligible persons in preparation for employment, or for individuals with paid jobs in a variety of settings and work sites, which may include individual or group options in the community and specialized industry settings.

**Before SSP changes** - DDD paid counties to contract with private vendors for employment services to help individuals find jobs. Long-term employment costs were then administered by counties through local provider agencies.

**After 2002 SSP changes** - The individual, or representative payee, receives a check and pays the local vendor directly.

**After 2003 Federal ruling** - Direct cash payments to individuals will continue for Employment/Day Program services, but will no longer be counted as SSP expenditures.

# STUDY OVERVIEW

## I. Research Method

Data for this report were collected from individuals with developmental disabilities, their families/guardians, state case managers, county staff, and service providers in three ways:

- 1) In May 2003, a mail survey was sent to families/guardians of all SSP recipients in the state. The surveys were conducted prior to the removal of restrictions to residential/VPP services and Employment/Day programs as a result of the federal ruling.
- 2) In the summer of 2003, focus groups were held with individuals with developmental disabilities, their families/guardians, county staff and service providers.
- 3) Individuals, their families/guardians, state case managers, county staff and service providers also were given the opportunity to provide comments via a questionnaire posted on the Developmental Disabilities Council (DDC) website.

More detail on the research methodology is provided under Appendix A.

## II. Participation Notes

**Family and Guardian Survey:** At the time of survey distribution, 2,859 SSP recipients in Washington State were using SSP funds to purchase Family Support, Employment/Day programs, and/or residential program services. Surveys were mailed to all families or guardians of the 2,859 SSP recipients.

The survey response rate was 27%, with 770 families/guardians responding.

**Focus Groups:** A total of 14 SSP Employment/Day recipients, 6 family members, and 18 county staff and providers participated in 5 focus groups around the state. Participation was not geographically representative. Three focus groups were held in King County, one in Wenatchee, and one with members of Self-Advocates In Leadership (SAIL). The three SAIL participants were from Spokane, Franklin/Benton, and Thurston counties.

The purpose of the focus groups was to talk about the SSP impacts with SSP recipients with developmental disabilities. Several methods were attempted to gather the perspectives from individuals without the influence of families or providers. Due to a number of factors, not withstanding a limited budget, these methods were not effective. Consequently, the focus group results should not be construed as purely SSP recipient perspectives. The focus group comments used in this report supplement the data derived from the mail surveys.

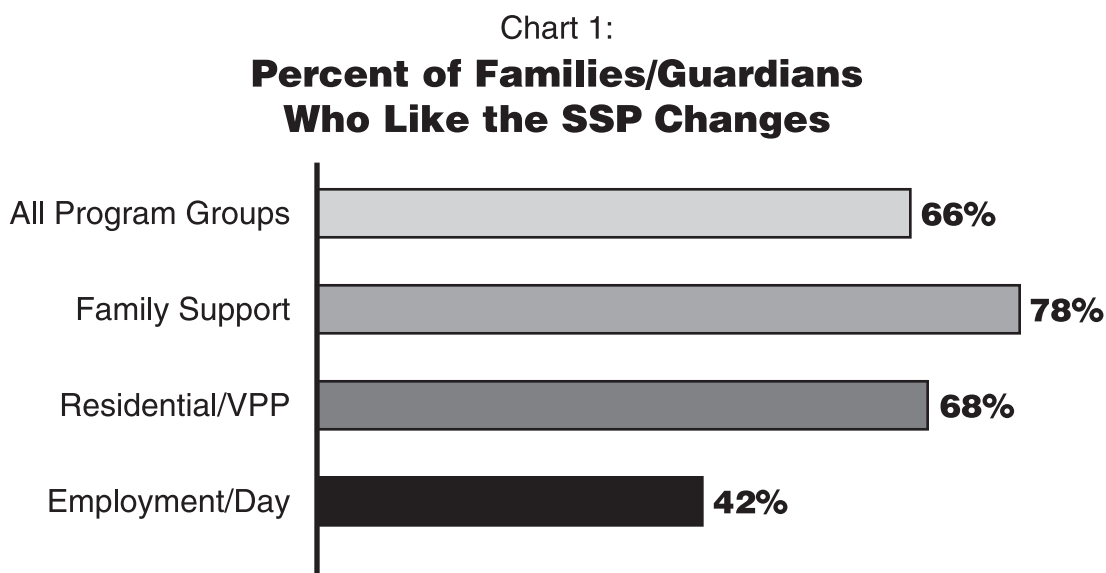
**Web Questionnaire:** An on-online questionnaire was posted on the DDC website. Notice of its availability was sent to qualified individuals along with their SSP payments. State case managers, county staff and service providers were notified of the website link through an email disseminated by the Division of Developmental Disabilities.

The on-line questionnaire was voluntarily completed by 221 individuals: 78-state case managers; 15-county staff; 80-service providers; and 48-individuals and/or family members/guardians. Results were voluntary and thus cannot be construed as representative of the total population.

# STUDY RESULTS

## I. GENERAL PERSPECTIVES: Families and Guardians

**Strong overall support for the SSP changes.** A significant majority of family/guardian survey responses (66%) indicate a strong level of overall support for the SSP changes. However, a more telling picture emerges when the responses are separated into the three different program groups. The Family Support group (78%) indicates the strongest level of support, followed by the Residential/VPP group (68%). Fewer of the Employment/Day group (42%) like the SSP changes.



Many family members/guardians expressed support for the SSP changes, citing increased flexibility, reduced 'red-tape', and expanded access to supports as primary reasons for their positive perceptions.

Several of the positive comments consist of simple expressions of thanks to DSHS and other agencies for their help meeting the needs of their family member with developmental disabilities, such as

### **Families & Guardians Generally Support SSP changes**

*"... I believe that changes to SSP have been positive... better than before."*

*"The SSP funds received directly have helped to make services and supports for my child more available as needed, and helped to simplify my life."*

*"Great program--it's the most efficient way for DSHS to provide resources that meets critical daily needs. This program empowers the recipient and case provider to make use of resources for individual client's unique case.."*

*“...as a parent, I am VERY GRATEFUL for all we are getting and for ANYTHING we get! Thank You!”*

Throughout the survey, the Employment/Day program group responses reveal an ambivalent or dissatisfied perception of the SSP changes.

Many of the comments focus on a perception that Employment/Day support recipients have incurred an increased burden (handling and managing support funds), with few if any beneficial increases in the flexibility or quality of supports.

### Employment/Day Group Express Concerns

*“Those of us who have a handicapped person to take care of already have more than enough to do... we had the option of choosing a different service provider without the money coming to us.”*

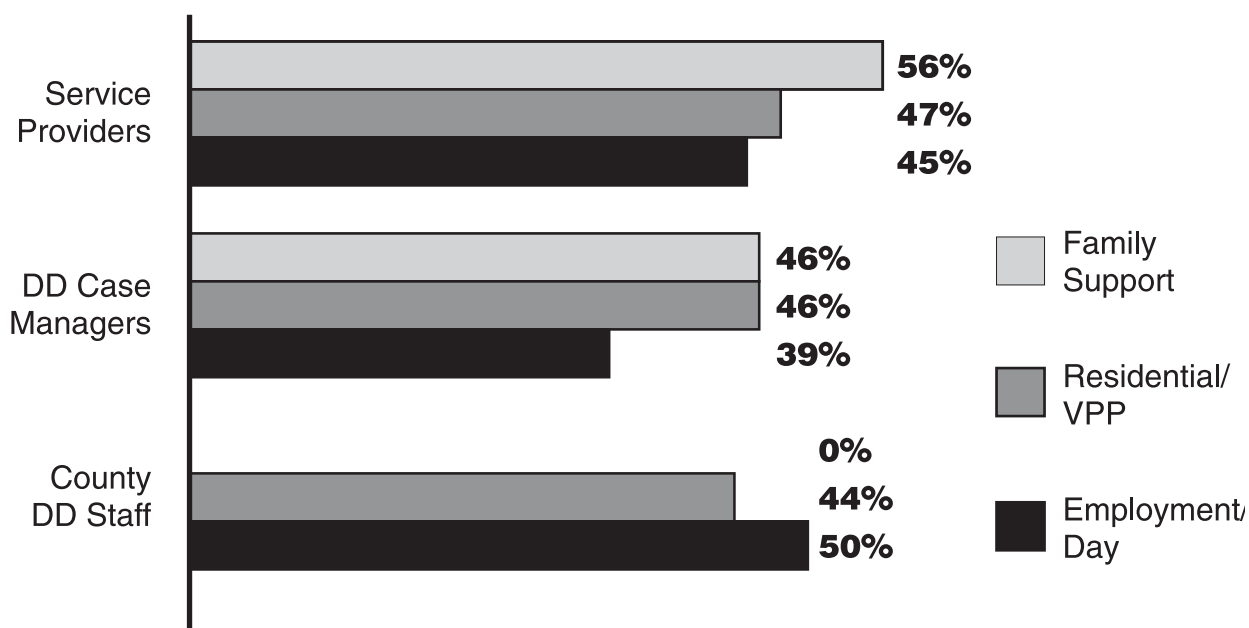
*“I feel it is ridiculous to add the extra step of sending the money to me first, and then I need to send it to them [the vendor]. What happens if the endorsed check gets lost? Or why should I take the time to first cash the check and then write another one?”*

*“Outwardly it appears that there are more choices but it actually equates to more responsibility without much change in the services.”*

## GENERAL PERSPECTIVES: Case Managers, County Staff, Service Providers

DD case managers/county staff and providers express some skepticism about positive impacts of SSP changes on individuals with developmental disabilities and their families. In most cases, less than half of the respondents indicate that the individuals they serve are being positively impacted by the changes in SSP.

Chart 2:  
**Percent of DD Professionals Indicating the SSP Is Having Positive Impacts**





Of the three service programs, the DD case managers/county staff and service providers from Employment/Day programs are the most skeptical, with only 39%-50% indicating a perception that SSP will have positive impacts.

DD case managers/county staff and service providers are concerned with a number of issues, including:

**Complexity:** Comments generally indicate that the SSP rules are complicated, unclear, and difficult to administer.

**Fairness:** Responses showed concern that the SSP changes took away funds from needy people. DD case managers/county staff also perceive an inequity of providing direct cash payments to some clients, and not others.

**Accountability:** Comments expressed specific concern about the lack of oversight of Family Support funds. Some worry that these funds are being absorbed into a family's general budget, and are no longer used to purchase items and support services specifically dedicated for their family member with developmental disability.

**Flexibility:** Concerns were expressed about the ability to receive and utilize SSP funds more flexibly. Several cited the need for SSP funds to be received in lump sums, or on a different payment cycle.

**Communication:** Several expressed a need for improved communication during the SSP changes between state DD case managers, county DD staff, service providers, and SSP recipients and their families/guardians.

## DD Case Manager/County Staff Concerns

*"It has added a layer of complexity to an already complex set of programs."*

*"It adds nothing to the power and choice of a client's life. The program is cumbersome to track and implement."*

*"It has been a nightmare to administer, and has had the effect of taking a little bit of money away from a lot of people, and given to a few people, many of whom already had other kinds of funded and natural supports."*

*"I do not know whether it [the SSP] is being used towards the individual with disabilities. There is no accountability."*

*"I would like to see the SSP suspended until it can run efficiently, fairly, and more responsibly."*

## Service Provider Concerns

*"I believe the current SSP system has resulted in fewer individuals being served, with more money going to fewer recipients."*

*"Families are still having trouble understanding what and how SSP can be used."*

*"The service provided to the SSP recipients has not changed yet the administration/cost that was added to the vendors to track and receive money plus the pressure it puts on the clients and their families seems unnecessary!"*

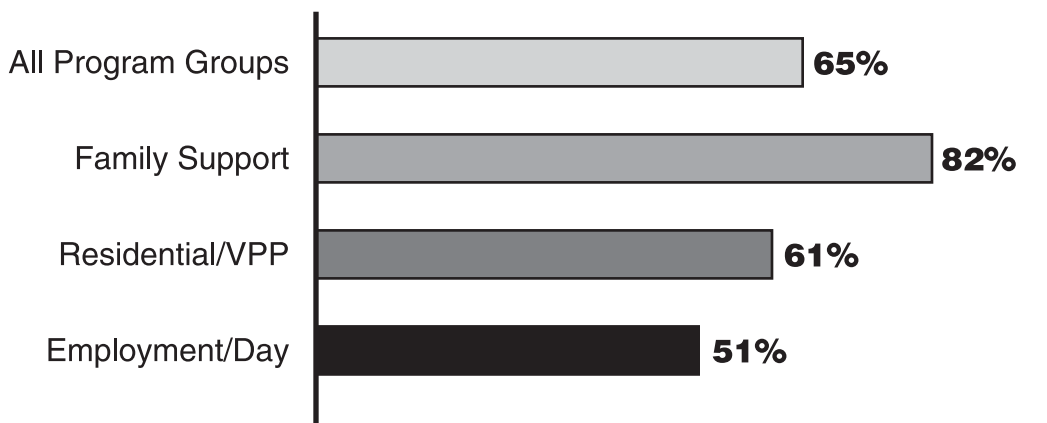
## II. SELF DETERMINATION: Families and Guardians

A primary reason cited by the Washington State Legislature for the SSP changes is a desire to promote individual and family self-determination. Self-determination is the ability of individuals to exercise control over their own lives and to assume responsibility for making choices and decisions based upon personal interests, abilities and preferences. From the overall perspective of families/guardians, the Legislature's effort has met a degree of success.

### **Overall, families/guardians see improvements in self-determination.**

A significant majority (65%) of family/guardian respondents indicate that the SSP change has encouraged individuals with developmental disabilities and their families/guardians to exercise self-determination. The three program groups offer differing responses, with the Family Support (82%) and the Residential/VPP (61%) groups indicating that the SSP positively enables their self-determination. The Employment/Day group (51%) responses are less positive.

Chart 3:  
**Percent of Families/Guardians  
Reporting Increase in Self-Determination**



Self-determination was measured by the respondents' perception of increased ability to choose supports, use supports not available before, change providers, and make own decisions about supports. Following are the responses for each of these categories.

**Ability to Choose Supports.** Less than half of the overall responses (46%) indicate that the SSP change increased family/guardian ability to choose their own supports.

Family/guardian respondents in Family Support experienced the most substantial increases in the ability to choose their own supports (59%), while only 38% of Residential/VPP and 25% of Employment/Day respondents cited a positive change.

**Ability to Use New Supports.** Overall, less than half of family/guardian respondents (47%) cite increases in the ability to use new supports not available to them prior to the SSP change. Family Support respondents experienced a higher ability (49%) than either Residential/VPP (41%) or Employment/Day (29%) groups.

**Ability to Change Providers.** Overall, few family/guardian respondents (28%) indicate an increase in their ability to change providers. Family Support respondents (35%) were more likely to see this ability increase than Employment/Day (19%) and Residential/VPP (16%) respondents.

**Ability to Make Own Decisions About Supports.** Half of the overall family/guardian responses (50%) indicate that the ability to make their own decisions has increased. However, responses separated into the three program groups reveal considerable differences. While 62% of the Family Support group cites increases, only 38% of the Residential/VPP and 31% of Employment/Day groups claim similar increases.

## Family Support Comments

### Flexibility and More Options

*“I like the way the program is set up now with us receiving the SSP funds and the flexibility of using them to greatest benefit of our daughter”*

*“I like having access to funds that were not able to be used prior to the changes. My daughter has more options this way.”*

### Self-Direction

*“We appreciate being able to decide what truly constitutes “family support” for our family.”*

*“This has helped “normalize” some of our daily activities making it easier to — “just go do things” and be part of the community. Planning and choices about who we do things with is much better.”*

## Employment/Day Comments

### Same Level of Supports, but More Responsibility

*“There was no increase in the amount of employment services available. We only pass on the check to the agency. We don’t feel having the power of having the money has increased our bargaining power with the agency.”*

*“I dislike having to manage these extra dollars and I think this change in SSP does not support self-determination.”*

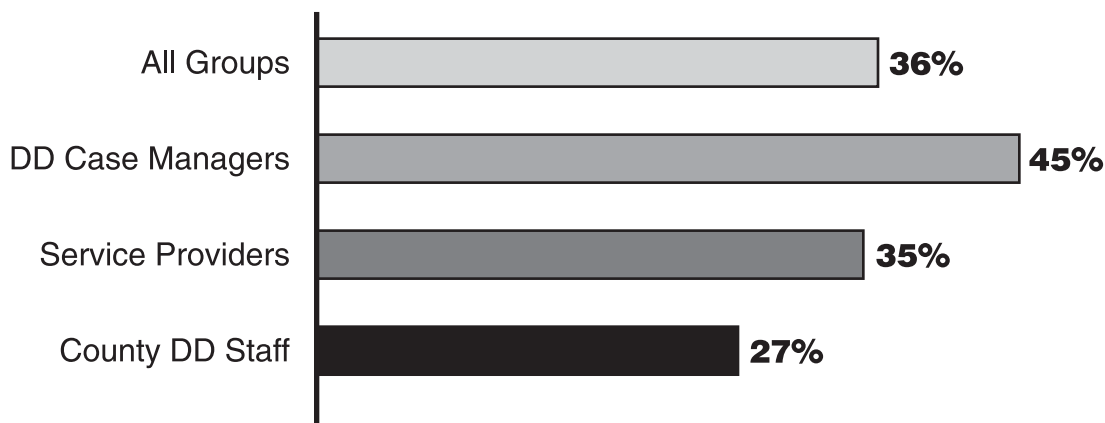
*“The only difference is, I have to deposit the check, then write a check back to her employment agency.”*

## SELF-DETERMINATION: Case Managers, County Staff, Service Providers

DD case managers/county staff and service providers are not encouraged about SSP’s potential to promote client choice and self-direction. Less than half of overall respondents (36%) believe the SSP change is increasing client choice and self-direction. State DD case managers (45%) are the most positive, while county DD staff (27%) and service providers (35%) were considerably less encouraged.

Chart 4:

### Percent of DD Professionals Perceiving Increased Client Choice and Self-Direction



Some comments provided by DD case managers/county staff and service providers reveal a concern that the SSP is too restrictive, and does not allow individuals with developmental disabilities and their families enough flexibility with their funds to properly exercise self-determination.

### **DD Case Manager/Staff and Service Provider Concerns**

*“Individuals and their families can only make the ‘choices’ that are available, which is often not REAL choice.”*

*“Families have more choice in some cases, but in others they are more restricted because the amounts of SSP are not to be saved from month to month for larger purchases.”*

*“I would like to see more flexibility in how individuals can use their employment-specific SSP funds. Right now, SSP uses are so restricted; there is no room for creativity!!!”*

## **III. HANDLING MONEY: Families and Guardians**

The Legislature altered the SSP by placing cash grants to purchase needed services directly into the hands of individuals with developmental disabilities, their families, guardians, or representative payees. This change raises an interesting set of questions regarding how, and to what extent families/guardians have been able to manage this new level of responsibility.

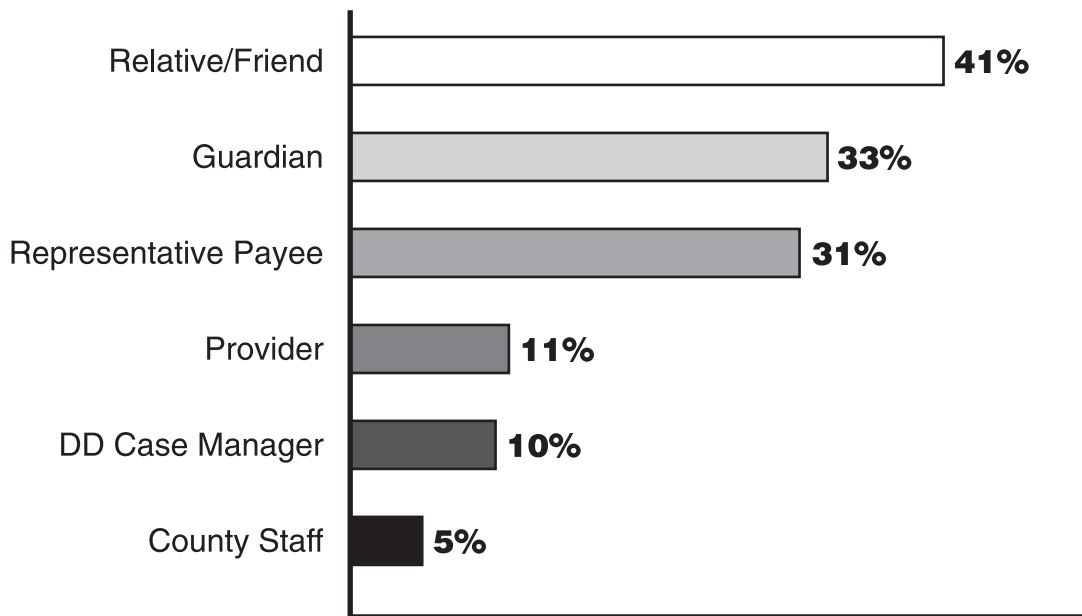
**Most are comfortable handling money.** An overwhelming majority of family/guardian respondents (83%), indicate that they are comfortable handling the money to pay for their supports. The Family Support group is the most positive about their new level of responsibility, while the Employment/Day and Residential/VPP groups express reservations.

**Most individuals rely upon relatives, friends, guardians and representative payees.** A majority (61%) of respondents indicate individuals are currently receiving help from someone else with managing the SSP funds. Of those receiving help, many rely upon relatives/friends (41%), guardians (33%) and representative payees (31%). Eleven percent (11%) state their service providers are assisting in this capacity.

**Family Support SSP-recipients like managing support money.** The majority of Family Support respondents (60%) like managing their support monies, while only 34% of Residential/VPP, and 25% of Employment/Day respondents feel the same.

**Family Support SSP-recipients like paying for their own supports, while other program groups are less supportive.** The majority of Family Support respondents (62%) indicate that they like paying for their own supports, while only 33% of Residential/VPP, and 27% of Employment/Day respondents feel the same.

Chart 5:  
**Individuals Have Help  
With Managing SSP Money**



**Respondents are less enthusiastic about the paperwork.** Forty-one (41%) of the Family Support group like the changes in paperwork requirements brought about by the SSP change, while only 19% of the Residential/VPP and 12% of Employment/Day groups view these changes positively. Only 26% of overall respondents cite increases in their paperwork responsibilities.

#### **Easier to Manage and Less Paperwork**

*“It’s one less task I need to do. I used to have to call in and hope the respite provider would be paid in a timely fashion or I would be reimbursed. Now I just pay it myself.”*

*“I like the change. It cut out having me to get justification letters from therapists, writing one myself, getting prices, sending it in, then having the committee approve or deny the request.”*

*“It’s so much more convenient, as money is now available whenever it’s needed. There’s no more waiting for approvals & proposals.”*

### **HANDLING MONEY: Case Managers, County Staff, Service Providers**

**Concerns about fiscal accountability.** Respondents expressed concern that SSP money is sent directly to families with little accountability for how this money is actually being

spent. The concern being the SSP funds will be mismanaged, thus jeopardizing individuals, providers, and the support system as a whole.

In addition, many respondents feel individuals may not know how to properly ascertain a provider's credentials or quality of service. State and county staff worry that placing the money in the hands of their clients leaves them open to manipulation and deceit.

Some service providers express an unease with having to handle situations where clients mismanage their SSP funds, yet still require services.

#### **Concerns about fiscal flexibility.**

Some respondents simply stated a need for more flexible payments (e.g. lump sums, rather than monthly payments) and different payment schedules (e.g. first of month payment, rather than last of month). Others suggested that SSP recipients negotiate their own rates and hours as a means of providing them with a higher level of control, quality, and accountability.

#### **DD Case Manager/Staff and Service Provider Concerns**

*"It is easy to understand why someone who lives in poverty would spend the money on whatever they choose and not what it is designated for."*

*"The client is the loser in this scenario if he/she loses his/her services as the result of choices made by irresponsible parents. The service provider loses because they are not being paid and the state loses because it is unlikely to recover these funds."*

*"The current system makes DDD clients victims of ambitious service providers. DDD clients are not savvy enough to recognize they are being victimized."*

*"My concern is with clients who can contract with anyone they choose, without regard for appropriateness of the contractor or the services they may provide. "*

*"I have not noticed that many agencies have really used the advent of SSP to change, improve, adapt, or personalize their services."*

## **IV. SERVICES: Families and Guardians**

Theoretically, allowing individuals and their families/guardians to pay their providers directly could allow them to demand and receive a higher quality of service and respect, and increased level of provider accountability.

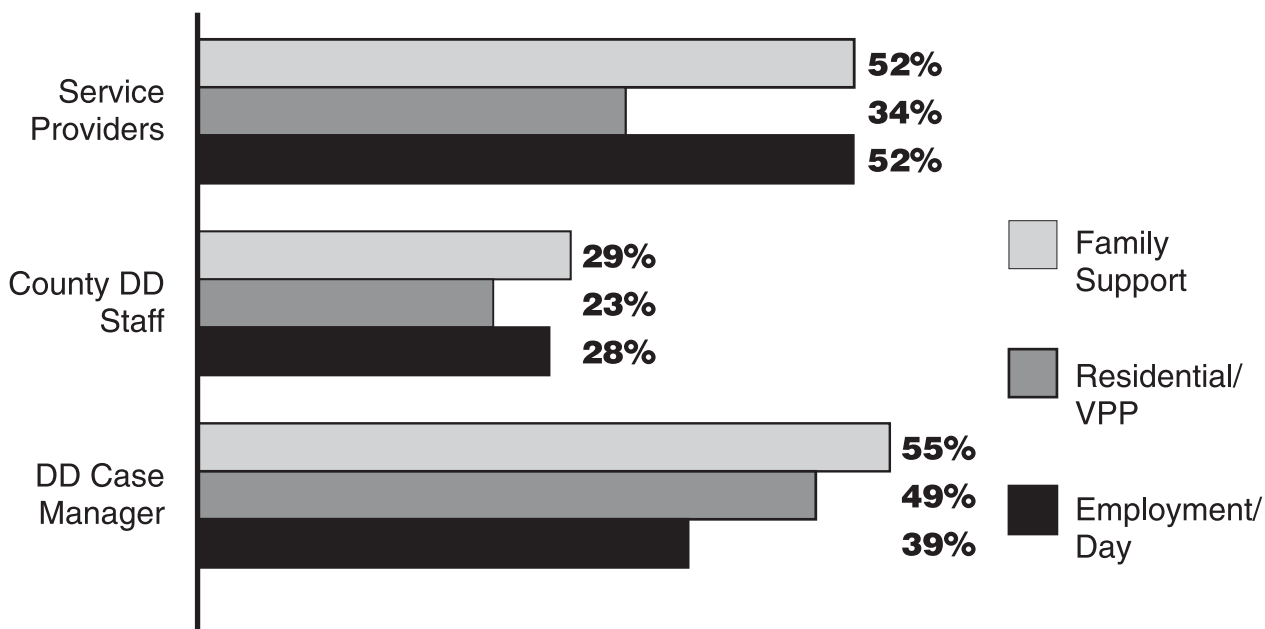
**Improved or no change in quality of supports:** Slightly more than half of Family Support (56%), and 49% of the Residential/VPP group indicate that the quality of their supports has improved since the SSP changes. Only 38% of Employment/Day respondents cited similar improvements. Forty percent (40%) of the Family Support group, 45% of the Residential/VPP group, and 58% of the Employment/Day group reported no changes.

Chart 6:  
**Percent of Families/Guardians  
Reporting Improved Quality of Supports**



**Improved or no change in relationships:** Fifty percent (50%) of families/guardians respondents cite increased levels of satisfaction with their DD case managers, 40% reported increased satisfaction with service providers and 29% reported increase satisfaction with the county DD staff. Many respondents (64%) indicate they have maintained the same level of contact with all professional staff since the SSP change.

Chart 7:  
**Percent of Families/Guardians  
Reporting Increased Satisfaction With Relationships**





### **Mixed review on provider accountability:**

Some of the family/guardian respondents described an enhanced sense of provider accountability with the new payment arrangements, and a new found understanding of how much providers charge for supports. This information is now used as a determinant factor when judging the quality of services.

Other family/guardian respondents expressed a frustration with the lack of change, or with a perception of a lack of provider accountability within the existing system.

Some comments address a perceived lack of provider oversight by state and county case managers to ensure that quality is uniform throughout the state.

### **Few Family/Guardian respondents have changed providers.**

Only 10% of family/guardian respondents changed providers since the SSP change. Some of the individual comments discuss concerns about a lack of providers in certain regions, especially rural areas. Geographic factors may be limiting the number of families opting for a provider or supports change in many areas.

### **SSP Enhances Provider Accountability—**

*“This has provided safe & reliable assistance. Self-determination and positive motivation for service provider to provide assistance rather than excuses.”*

*“A bonus is that the service provider has been more accountable--now that we know how much they get each month--that alone has made the extra time involved in handling the SSP payment worthwhile!”*

*“[The SSP change] increased choice. It did make a difference—more accountability.”*

### **Some Accountability Concerns Remain—**

*“Not enough oversight over providers; inability to insure that the individual plan is adhered to; insufficient flexibility in provider services.”*

*“The biggest issue that causes me great concern is the lack of accountability within the system now. We have no power to make the provider find more hours for our son except for firing them and looking for a new provider.”*

*“I would like to know how [the state and vendors] set how much money vendors receive for services.”*

## V. UNINTENDED IMPACTS: Families and Guardians

The alterations to the SSP changed how some individuals with developmental disabilities and their families manage and utilize their supports. Many SSP recipients receive other benefits including SSI, welfare, Medicare, food stamps, and other assistance to help pay for their special needs.

**Few families/guardians lost eligibility for benefits.** Only 5% of family/guardian respondents indicate their benefit eligibility was impacted by the SSP change. While 5% is a small percentage overall, this represents approximately 38 families that have experienced some level of difficulty with their benefit eligibility status as a result of the SSP changes. Given that this survey represents less than thirty percent of the entire SSP population, it is conceivable that the total number of families experiencing problems with their eligibility is much larger now, and into the future.

### Concerned about SSI Status

*“I like the choice to handle the purse strings, though it’s bad that it’s tied to SSI.”*

*“SSI mis-pays every month, which is so much paperwork already. An insurance policy taken out when my son was born, nearly caused him to lose his SSI when he turned 21.”*

*“The only downfall to the SSP is if my child is in need of expensive equipment, I cannot save up for that equipment without affecting SSI, which only allows a certain amount of assets.”*

Many family/guardian survey respondents and focus group participants were specifically concerned that accumulated SSP funds could potentially jeopardize their SSI eligibility.

**UNINTENDED IMPACTS: Case Managers, County Staff, Service Providers****Constant Threat of Losing**

**Funds.** DD case managers/county staff and service providers expressed similar concerns as families, guardians and individuals about SSI eligibility. From their perspective, clients lacking the skills to manage their SSP funds have a constant threat of losing funds.

Many recommended that SSP recipients have more flexibility in the use of their funds, including the ability to save their funds or combine them with other income, without running afoul of SSI resource limits.

Individuals who lose their SSP due to mismanagement of funds face the possibility of being dropped from the SSP on a permanent basis.

**Concerns about Income Limitations and Penalties**

*“We lost our SSP because we went over the gross income limits...I think the whole SSP thing has made life harder.”*

*“I would like us to be able to earn more money without being penalized.”*

*“If he earns more, he’ll lose his Medicaid.”*

*“It jeopardizes supports available to a client if the client does not use it appropriately (due to poor judgment which most of our clients have).”*

*“This has created a situation in which every month on the first between SSI, wages, food stamps, and two kinds of SSP, this person comes close to exceeding the SSI/Medicaid resource limit until the day program SSP is paid to the vendor.”*

*“Hold SSP harmless as a resource from Social Security, and allow folks to save it up if they want to purchase services.”*

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# FINDINGS & OBSERVATIONS

## I. Findings

This report represents a first year assessment of the impacts of SSP changes on individuals with developmental disabilities, their families, and the community that serves them. While the SSP transition is still evolving, the **findings** of this research indicate:

### ■ **Families and Guardians Like the SSP Changes**

Overall, SSP direct cash payments is well-received by families and guardians, especially Family Support respondents.

### ■ **Employment/Day Respondents Have More Concerns**

Employment/Day Program family and guardian respondents are less enthusiastic in all areas of SSP changes (self-determination, handling money, service quality and accountability, and unintended impacts). Many cite extra responsibility without much change in service. Individuals with developmental disabilities and their families/guardians are now able to see how much their supports cost, yet many report that the quality of the services they receive has not improved.

### ■ **Case Managers, County Staff and Service Providers Express Concerns**

DD case managers and county DD staff express concerns about issues related to complexity, fairness, accountability, and flexibility. Their primary concern is that the lack of oversight and accountability of the SSP funds will result in families spending the dollars on something other than the special needs of the family member with the developmental disability. Service providers are mostly concerned about communication within the DD system, and flexibility/payment issues.

### ■ **Self-Determination Enhanced**

Overall, family and guardian respondents perceive enhanced self-determination in their ability to choose supports, change providers, and make decisions about needed supports. Again, Family Support respondents reported self-determination enhancement more often than Residential and Employment/Day respondents. DD case managers/county staff and services providers are more skeptical about the positive impacts of SSP on client choice and self- direction.

### ■ **Handling Money Not a Problem**

Most family and guardian respondents are comfortable handling the SSP money. Most individuals receive help managing the money from relatives, friends, guardians, representative payees, or providers.

## ■ Few Individuals are Falling through the Cracks

Some people are falling through the cracks-losing eligibility for other benefits due to SSP changes. While the percentage reporting lost benefits are few, it is disconcerting that people are experiencing lost benefits, given the vulnerability of this population.

## II. Observations

Based on these findings, the research team provides the following **observations** for consideration by the Washington State Legislature, Developmental Disabilities Council, and the Washington State Division of Developmental Disabilities. Points of discussion are suggested for each observation

### **Why are Employment/Day SSP-recipients not as satisfied?**

Employment/Day respondents expressed many reservations about the changes to the SSP. They are not seeing their choices, quality and availability of their supports improve. Perhaps the existing restrictions limit the ability of these recipients to enjoy the same self-determination and choice improvements as reported by Family Support recipients. Or, perhaps the dissatisfaction is due to the perception that the service does not warrant the pay.

- a) Is it feasible to establish a regional pilot that removes or lifts many of the restrictions governing how and where Employment/Day supports are spent and evaluate the impacts on employment?
- b) Is it time to review the existing rate and payment structure for Employment/Day programs? Or educate recipients on how the rate structure works?
- c) Is a fee-for-service reimbursement structure more appropriate rather than the current managed structure?
- d) Should clients be allowed to negotiate rates and hours for services?

### **Should SSP payments be more flexible?**

Many respondents suggested making the SSP more flexible. The following are some of these suggested options:

- a. **Lump sum payments** - Is it possible for SSP recipients to receive their cash grants in lumps sums so they may purchase major items?
- b. **Timing** - Can payments be made quarterly, rather than monthly?
- c. **Termination** - Can individuals be allowed to get back into SSP once their SSP payments have been terminated?

- d. **Variation** - Can amounts be increased or decreased from month to month when significant life changes occur for the individual?
- e. **Voluntary** - Can SSP recipients “opt in or out” of the SSP direct cash payments?
- f. **Vouchers** - Would a voucher program be feasible, where clients pick their needed services and use a voucher for payment?

### **How can economic disincentives be eliminated?**

Economic disincentives appear to be built into the benefit system by the Social Security Administration (SSA), artificially depressing the options for working individuals with developmental disabilities.

- a) Is it feasible to work with SSA to eliminate income restrictions allowing individuals with developmental disabilities who work to increase job-related income without jeopardizing eligibility for needed benefits?
- b) Can “protected” individual trusts enable people to avoid the income caps while saving money?

### **Should accountability and safety be improved?**

The SSP changes intended to encourage self-determination, which theoretically could expose individuals with developmental disabilities and their families/guardians to potential risks and consequences.

An inherent tension arises when increasing self-determination for this population. Will family decisions lead to increased risks? Can families be trusted to be accountable, and spend the funds on needed services for the individual with developmental disabilities? The findings of this study clearly illustrate these tensions.

- a) What are the acceptable levels of risk in a self-directed system?
- b) Should state and local guidelines ensure acceptable levels of risk are not exceeded?

**Can equity and fairness be improved?**

Some SSP recipients receive more benefit and supports money than others who have similar needs and disabilities. DDD clients who are not SSP recipients must comply with requirements of which SSP recipients do not. Can these inequities be addressed?

- a) Is there a way to more equitably distribute SSP funds? Or easily communicate the distribution method?
- b) Should other non-SSP recipients, DDD clients be considered for receiving direct cash payments?

**What lessons can be learned?**

Short timeframes and evolving direction has made the administration of the SSP burdensome and complex. Now that the dust has settled somewhat,

- a) Are there ways to enhance communication and training strategies that make the SSP less complex and easier to administer?
- b) Is a communication strategy in place that can help with implementation of future policy changes?

**III. Conclusion**

Policy makers and technical professionals in the field of developmental disabilities should further analyze the results and findings from this first year assessment of the SSP.

There are a number of lessons to be learned from this first year study. Appropriate changes to the SSP should help to ensure that individuals with developmental disabilities, their families, and their support system continue to work together for the mutual benefit of the entire population. The changes brought about in 2003 by the Social Security Administration's disallowance of some SSP expenditures will also require a careful reassessment of the SSP system.

In the fall of 2004, a second year assessment of the SSP will be published. The data will provide a longer-term analysis of the SSP impacts on individuals with developmental disabilities, their families, and the community that serves them. The 2004 report will also take into consideration the ongoing 2003 SSP changes mandated by federal requirements.

Based on the data and analysis of both 2003 and 2004 reports, a set of recommendations will be developed and presented to both DSHS and the 2005 Washington State Legislature to address the major points outlined in the reports.



## APPENDIX A: METHODOLOGY

The 2003 SSP Evaluation Project monitored and evaluated the implementation of the State Supplementary Payment (SSP) cash payment as a means of determining the potential impacts on individuals with developmental disabilities, families, and the communities that serve them.

With oversight of an advisory group, the evaluation project followed three population groups to assess the impacts of the SSP distribution changes. The following methodologies were utilized:

Population Group	Evaluation Methodology	Outcomes Measured
<b>Individuals with Developmental Disabilities and Their Families or Guardians</b>	A mail survey for families or guardians; focus groups for individuals with developmental disabilities; and a web-based questionnaire.	<ul style="list-style-type: none"> <li>✓ Changes in self-determination</li> <li>✓ Change in service flexibility</li> <li>✓ Change in reporting requirements</li> <li>✓ Change in eligibility for income-eligible programs</li> <li>✓ Changes in client satisfaction</li> <li>✓ Changes in accountability</li> <li>✓ Possible impacts to clients and services</li> </ul>
<b>State and County DD Staff</b>	Feedback obtained via a web-based questionnaire. Some staff attended client focus groups.	<ul style="list-style-type: none"> <li>✓ Change in ability to serve DDD population</li> <li>✓ Changes in quality levels of service</li> <li>✓ Possible impacts to clients and services</li> </ul>
<b>Service Providers</b>	Feedback obtained via a web-based questionnaire. Some staff attended client focus groups.	<ul style="list-style-type: none"> <li>✓ Change in viability</li> <li>✓ Change in reporting requirements</li> <li>✓ Changes in quality levels of service</li> <li>✓ Possible impacts to clients and services</li> </ul>

## MAIL SURVEY

### Population/Sample Comparisons

Surveys mailed early May 2003

Deliverable surveys sent 2859

Returned 770

Response Rate 27%

The response rate is low, but the sample is robust. Mail surveys traditionally have low rates of return. Statistically, a sample size of 770 is excellent.

### Region:

	Population	Sample
<b>Region 1</b> (Eastern Washington)	21%	20%
<b>Region 2</b> (Yakima, Walla Walla and S. Central WA)	10%	9%
<b>Region 3</b> (Skagit, Snohomish, Whatcom, San Juan, Island)	12%	13%
<b>Region 4</b> (King)	24%	19%
<b>Region 5</b> (Kitsap, Pierce)	18%	18%
<b>Region 6</b> (Thurston, Clark, Lewis, Mason and W. WA)	15%	21%

Good regional representation is in sample, though somewhat under sampled in Region 4 (King County), and somewhat over sampled in Region 6. The sample is regionally representative.

### Survey Responses Grouped by Supports:

Supports	Population	Sample
Family Support	65%	49%
Employment/Day	14%	36%
Residential/VPP	21%	15%

These data sets include multiple counts for those utilizing more than one support service. Employment/Day is over sampled and Family Support and Residential/VPP are under sampled. While this raises the question of whether the sample is representative with regard to Family Support, there are sufficient numbers of Employment/Day and Residential/VPP respondents for a statistical analysis.

## FOCUS GROUPS

The research team gathered qualitative data from individuals with developmental disabilities and their families via focus groups in the summer of 2003. The Region 4 focus group was conducted in Wenatchee, while three sessions were held in Region 1, at three separate locations. In addition, a meeting was held in Thurston County with members of Self Advocates In Leadership (SAIL).

The research team employed several methods as a means of reaching out to individuals with developmental disabilities. However, budget constraints and logistical problems undermined the successful achievement of a true regional representation of personal perspectives within the state. Laws pertaining to confidentiality prevented the research team from directly contacting individuals with developmental disabilities and their families, thus the team was reliant upon service providers and county staff to reach out to potential focus group participants. Transportation and scheduling difficulties also intervened as a further complication.

Focus group data in this report are therefore not intended to represent the overall opinions of SSP recipients and their families/guardians, rather, these data are a supplemental addition to the more regionally representative responses captured in the mail survey.

	Individuals	Family Members	County DD Staff
King County	7	4	6
Wenatchee	4	2	12
Self Advocates in Leadership	3	0	0

## ONLINE QUESTIONNAIRES

Individuals with developmental disabilities and their families, state DD case managers, county DD staff, and service providers were offered the opportunity to provide their perspectives via an online questionnaire in the summer and fall of 2003. The questionnaire is available on the DDC web page at: [www.ddc.wa.gov/SSP/questmain.html](http://www.ddc.wa.gov/SSP/questmain.html).

Clients were sent invitations printed on inserts mailed along with their SSP checks in July of 2003. State DD case managers, county DD staff, and service providers were sent email invitations the next month in early August. The deadline for on-line submissions was set for September 19, 2003. There were 221 total questionnaires returned:

- 78 State DD case managers
- 15 County DD staff
- 80 Service Providers
- 48 Clients and/or Families

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# APPENDIX B: Family and Guardian Survey

## STATE SUPPLEMENTARY PAYMENT (SSP) - SURVEY

Please answer all of the following questions to the best of your ability. If you have additional comments on any of the questions, please list those comments at the end of the survey (question 21). All responses are anonymous and confidential. Please return your completed survey to the DDC.

In this survey “supports” are defined as: family support programs, respite care, professional therapies, transportation, residential services, parent/family counseling, environmental modifications, training, and employment/day services, etc.

### Section I - How changes to SSP are affecting your life

1. Have your skills, knowledge, responsibilities and other factors increased or decreased since the changes to SSP? Do you like or dislike these changes? *(For each question, check the box that best applies to you in both Column A and Column B)*

#### SELF-DETERMINATION IN ...

a.	Choosing your own supports?
b.	Using supports you couldn't use before?
c.	Changing providers of supports?
d.	Making own decisions about supports?

COLUMN A			
Increased	Decreased	Unsure	No change

COLUMN B			
I like the change	I dislike the change	Unsure	No change

#### RESPONSIBILITY FOR...

e.	Arranging for supports?
f.	Paying for supports?
g.	Managing the money for supports?
h.	Filling out paperwork involved with supports?



#### AMOUNT OF...

i.	Supports available?
j.	Time arranging for supports?
k.	Knowledge you need to have about supports?



2. To what extent have you been able to exercise self-determination through the SSP?

- 1 - ☐ To a great extent      2 - ☐ To a moderate extent  
 3 - ☐ To little extent      4 - ☐ To no extent

3. With the SSP changes, are supports better or worse in the following areas?  
*(circle one number for each)*

		Much better	Somewhat better	No change	Somewhat worse	Much worse
a.	Amount	5	4	3	2	1
b.	Quality	5	4	3	2	1
c.	Health and safety	5	4	3	2	1
d.	Security	5	4	3	2	1
e.	Flexibility	5	4	3	2	1
f.	Access	5	4	3	2	1
g.	Cost	5	4	3	2	1
h.	Availability	5	4	3	2	1

4. Overall, do you like or dislike the changes in the SSP? *(check one)*

- 1 - ☐ I like the changes a lot  
 2 - ☐ I like the changes a little  
 3 - ☐ I dislike the changes a little  
 4 - ☐ I dislike the changes a lot  
 5 - ☐ Doesn't matter to me

## Section II - Handling money

5. Is anyone helping you manage your SSP? *(check one)*

- 1 - ☐ Yes *(if yes, continue to Question 6)*  
 2 - ☐ No *(if no, please move on to Questions 7)*

6. a. Who helps you to manage your SSP? *(check all that apply)*

- 1 - ☐ relative/friend    2 - ☐ county staff    3 - ☐ provider    4 - ☐ DDD case manager  
 5 - ☐ representative payee    6 - ☐ guardian    7 - ☐ other \_\_\_\_\_

b. What concerns, if any, do you have about this arrangement? \_\_\_\_\_

7. Are you currently receiving enough money from DSHS/DDD to purchase the needed supports you received before the change in the SSP? *(check one)*  
1 - ☐ Yes                      2 - ☐ No                      3 - ☐ I Don't Know
8. Since the SSP change, are you using more of your own money to help pay for needed supports? *(check one)*  
1 - ☐ Always                      2 - ☐ Sometimes                      3 - ☐ Never
9. If you directly employ an individual to provide supports, how comfortable or uncomfortable are you with the following? *(circle one number for each question)*

**NOTE: Skip this question if you use an agency to provide supports, or if you don't employ anyone.**

		Very Comfortable	Somewhat Comfortable	Very Uncomfortable	Doesn't Apply to Me
a.	Paying People?	4	3	2	1
b.	Handling taxes and other record keeping	4	3	2	1
c.	Obtaining background checks and other screening	4	3	2	1
d.	Assuming risks and liabilities	4	3	2	1

10. Overall, how comfortable or uncomfortable are you with handling the money to pay for supports? *(check one)*

- 1 - ☐ Very comfortable  
2 - ☐ Somewhat comfortable  
3 - ☐ Somewhat uncomfortable  
4 - ☐ Very uncomfortable

### Section III - Your relationship with providers and case managers.

11. Since the changes in the SSP, do you have more or less contact with your case manager? *(check one)*  
1 - ☐ More contact    2 - ☐ Less contact    3 - ☐ About the same    4 - ☐ Not enough contact

12. Since the changes in the SSP, are you more or less satisfied with:

(enter 1-5 for each question)

5 = Very Satisfied 4 = Somewhat Satisfied 3 = No Change

2 = Somewhat Less Satisfied 1 = Much Less Satisfied

		DDD Case Manager	DD County Staff	Direct Service Provider
a.	Amount of contact with ...	3	2	1
b.	Your relationship with ...	3	2	1
c.	The information shared with you about changes in the SSP	3	2	1

13. Did you change providers and/or supports as a result of the SSP change? (check one)

1 - ☐ Yes 2 - ☐ No 3 - ☐ Not currently 4 - ☐ Don't know

14. Is it easier or harder to work with providers since the changes in the SSP? (check one)

1 - ☐ A lot easier 2 - ☐ A little bit easier 3 - ☐ No change

4 - ☐ A little bit harder 5 - ☐ A lot harder

## Section IV - Other Information

15. When did you first start receiving the SSP?

Month

Year

16. In which county do you currently receive most of your supports?

\_\_\_\_\_

17. What supports do you currently pay for with SSP? (Check all that apply)

1 - ☐ Family Support Services 2 - ☐ Employment/Day programs 3 - ☐ Residential

4 - ☐ Voluntary Placement Programs (VPP)

18. As a result of changes to the SSP, have you lost eligibility for other benefits such as food stamps, welfare, Section 8 housing, etc.?

1 - ☐ Yes If yes, what programs? \_\_\_\_\_

2 - ☐ No

3 - ☐ I don't use these programs



19. Have your Supplemental Security Income (SSI) benefits been affected by the changes in the SSP?

1 - ☐ Yes - *If yes, how?* \_\_\_\_\_  
 2 - ☐ No      3 - ☐ Not yet - *Explain* \_\_\_\_\_

20. What other activities have been impacted by changes to the SSP (e.g. guardianship, care plans, wills/trusts, cash flow, banking, etc.)? \_\_\_\_\_

21. Other comments regarding changes to the SSP?  
*(You are welcome to provide comments on a separate piece of paper and include it with the survey in the return envelope.)*

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**THANK YOU FOR YOUR PARTICIPATION!**  
 PLEASE RETURN SURVEY IN THE  
 ENCLOSED SELF-ADDRESSED, STAMPED ENVELOPE, OR MAIL TO:  
 Developmental Disabilities Council, P.O. Box 48314, Olympia, WA 98504-8314

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# APPENDIX C: Online Questionnaire

SSP- Individuals with Developmental Disabilities, Family and Guardians Questionnaire  
In this questionnaire, “supports” are defined as: family support programs, respite care, professional therapies, transportation, residential services, parent/family counseling, environmental modifications, training, and employment/day services, etc.

Are you a person with developmental disabilities?	Are you a family member or guardian of a person with developmental disabilities?
<input type="checkbox"/>	<input type="checkbox"/>

If you have filled out our mail survey, please check here: ☐

1. Do you have a personal story about your experiences with the SSP (good or bad) that you would like to share?

If you only want to tell your story and not complete the rest of the questionnaire,  
[click here to skip to the end](#)

2. What do you like or dislike about the changes to the SSP? (select one box for each question)

	I like a lot	I like it a little	I have no feelings one way or the other	I dislike it a little	I dislike a lot	This does not apply to me
a. The ability to make my own decisions about supports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. The handling of money/payment for supports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. The flexibility to change my supports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. My ability to sue supports I could not use before	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. Who helps you manage your SSP? (select all that apply)

Myself <input type="checkbox"/>	A Relative/ Friend <input type="checkbox"/>	County Staff <input type="checkbox"/>	Provider <input type="checkbox"/>
DDD Case Manager <input type="checkbox"/>	Representative Payee <input type="checkbox"/>	Guardian <input type="checkbox"/>	Other <input type="checkbox"/>

---

4. How comfortable or uncomfortable are you with handling the money to pay for services or supports? (select one box only)

Very comfortable	Somewhat comfortable	Somewhat uncomfortable	Very uncomfortable
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

5. Since the SSP change, are you using more of your own money to help pay for needed support? (click one box only)

Always	Sometimes	Never
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

6. Are you satisfied with your relationship with case managers and service providers since the SSP changed? (click one box only)

Very satisfied	Somewhat satisfied	No Change	Somewhat less satisfied	Much less satisfied
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

7. Did you change providers and/or supports as a result of the SSP change? (click one box only)

Yes	No	Not Currently	Don't Know
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

8. What changes if any would you like to see in the SSP?

Please be aware that while we are making every effort to protect your privacy, information sent over the Internet is not 100% secure. If you choose to participate in this questionnaire, please do not use any person's name, home address, phone number, or e-mail address.

[Submit Survey](#)

[Clear Form](#)

If you are experiencing problems related to abuse, neglect or financial exploitation please report these to the Child/Adult Abuse toll free Hotline 1-866-ENDHARM (1-866-363-4276)

If you have questions or comments about this web site contact us at the [DDC Web](#).

### SSP- DDD Case Managers and County DD Program Administrators Questionnaire

Have you responded to a DDC SSP questionnaire (in any format) in the last:

6 Months	12 Months	18 Months	24 Months	Never
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Are you a DDD Case Manager?

☐

Are you a County DD Program Administrator?

☐

1. Please indicate the services that best describe those SSP supports you provide for people in your caseload/program: (check all that apply)

Residential services and supports	Employment or Day programs	Family support services	Other
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you checked other, please describe:

2. Do you believe the changes to the SSP increase or decrease the choice and self-direction of individuals with developmental disabilities? (click one)

Greatly increase	Somewhat increase	No change	Somewhat decrease	Greatly decrease	No opinion
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

3. Please indicate the likelihood the SSP change is having positive impacts on each of the following areas: (click one for each)

a. Individuals with developmental disabilities and their families?		
Very likely	Somewhat likely	No positive impact
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

b. Service providers?		
Very likely	Somewhat likely	No positive impact
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

c. Your region's developmental disabilities programs?		
Very likely	Somewhat likely	No positive impact
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

4. Please indicate the likelihood the SSP change is having negative impacts on each of the following areas: (click one for each)

a. Individuals with developmental disabilities and their families?		
Very likely	Somewhat likely	No negative impact
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

b. Service providers?		
Very likely	Somewhat likely	No negative impact
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

c. Your region's developmental disabilities programs?		
Very likely	Somewhat likely	No negative impact
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

5. Has the new SSP changed your day-to-day workload significantly? (click one)

It has increased my workload significantly	It has increased my workload somewhat	There has been no appreciable change	It has decreased my workload somewhat	It has decreased my workload significantly
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6. What changes if any would you like to see in the SSP?

Please be aware that while we are making every effort to protect your privacy, information sent over the Internet is not 100% secure. If you choose to participate in this questionnaire, please do not use any person's name, home address, phone number, or e-mail address.

<input type="button" value="Submit Survey"/>	<input type="button" value="Clear Form"/>
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If you are experiencing problems related to abuse, neglect or financial exploitation please report these to the Child/Adult Abuse toll free Hotline 1-866-ENDHARM (1-866-363-4276)

If you have questions or comments about this web site contact us at the [DDC Web](#).

## SSP - Service Provider Questionnaire

Have you responded to a DDC SSP questionnaire (in any format) in the last:

6 Months	12 Months	18 Months	24 Months	Never
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

1. Please indicate the supports your facility/program provides to individuals with developmental disabilities: (check all that apply)

Residential care	Employment or Day programs	Family support services	Other:
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you checked other, please describe:

2. Do you believe the changes to the SSP increase or decrease the choice and self-direction of individuals with developmental disabilities? (click one)

Greatly increase	Somewhat increase	No change	Somewhat decrease	Greatly decrease	No opinion
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3. Please indicate the likelihood the SSP change is having positive impacts on each of the following areas: (click one for each)

a. Individuals with developmental disabilities and their families?		
Very likely	Somewhat likely	No positive impact
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



b. Your agency?

Very likely

Somewhat likely

No positive impact



4. Please indicate the likelihood the SSP change is having negative impacts on each of the following areas: (click one for each)

a. Individuals with developmental disabilities and their families?

Very likely

Somewhat likely

No positive impact



b. Your agency?

Very likely

Somewhat likely

No positive impact



5. Has the new SSP changed your day-to-day workload significantly? (click one)

It has increased my workload significantly

It has increased my workload somewhat

There has been no appreciable change

It has decreased my workload somewhat

It has decreased my workload significantly



6. Has the new SSP changed the way your agency functions? (click one)

It has significantly changed how my agency functions

It has changed the way my agency functions somewhat

There has been no appreciable change in my agency



7. Have the SSP changes impacted your contractual relationship with the DSHS Division of Developmental Disabilities? (click one)

The Contractual relationship has been positively impacted	The Contractual relationship has been somewhat impacted	The Contractual relationship has not been impacted	The Contractual relationship has been somewhat impacted	The Contractual relationship has been negatively impacted
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

8. What changes if any would you like to see in the SSP?

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Please be aware that while we are making every effort to protect your privacy, information sent over the Internet is not 100% secure. If you choose to participate in this questionnaire, please do not use any person's name, home address, phone number, or e-mail address.

Submit Survey

Clear Form

If you are experiencing problems related to abuse, neglect or financial exploitation please report these to the Child/Adult Abuse toll free Hotline 1-866-ENDHARM (1-866-363-4276)

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## APPENDIX D: Focus Group Protocols

### Cover Letter

Dear \_\_\_\_\_

We are writing to ask for your feedback on your experiences with the changes in the State Supplemental Payment (SSP).

As you know, the SSP changed in July 2002 so that eligible clients of the Department of Social and Health Services, Division of Developmental Disabilities (DHS/DSD) or their guardians directly receive money to purchase services such as family support services, employment or transition services, and/or residential services.

The Developmental Disabilities Council (DDC) has hired a consulting firm to monitor the impacts of the SSP change on individuals with developmental disabilities and their families over a two-year period.

As part of this assessment, we'd like you to participate in a focus group discussion of the SSP changes. Focus groups are small group discussions focused on a topic. You will be joined by other individuals with developmental disabilities who also receive the SSP. The discussion will be conducted by trained facilitators and will last no more than 1 1/2 hours.

The conversation will be tape-recorded but the results will be confidential. While we may use quotes from the group in our reports, no one person's responses will be identifiable. The DDC will use the information from the focus groups to inform and provide recommendations to Washington state agencies and the Legislature.

The focus group discussion will be held on [DATE, at TIME, and PLACE.] Transportation to and from the meeting will be provided by the host facility. Participants will be offered \$20.00 to help defray costs of participation, and refreshments will be provided as well.

The discussion will focus on how the changes in the SSP have or have not affected you. An informed consent form will need to be signed and returned in order to participate in the discussion.

If you have any questions about the study or concerns about your participation in the study, please contact the DDC at: 1-800-634-4473, or [ddc@cted.wa.gov](mailto:ddc@cted.wa.gov)

Thank you very much for your valuable contribution.  
Sincerely,

Ed Holen  
Executive Director— Developmental Disabilities Council

## Informed/Consent

I, \_\_\_\_\_, hereby agree to serve as a participant in the research project entitled “Assessing the Impacts of Changes in the SSP.” It has been explained to me that the purpose of this study is to assess and monitor how changes in the SSP affect individuals with developmental disabilities. I understand that the proposed use for the research, now and in the future, is to inform and provide recommendations to the Washington State Legislature.

I understand that the possible risks to me associated with this study are minimal.

I also understand that I may not receive any direct benefit from participating in this study, but my participation may help us better understand the changes in SSP.

The researchers have offered to answer any questions I may have about the study and to provide me with access to the final report or presentation.

I understand that in the event I experience problems as a result of my participation in this project I should contact the DDC at: 1-800-634-4473, or [ddc@cted.wa.gov](mailto:ddc@cted.wa.gov)

I understand that if I am having any problems related to abuse, neglect, or financial exploitation I should contact the Child/Adult Abuse toll free Hotline 1-866-ENDHARM (1-866-363-4276).

I hereby agree to participate as a participant in the above-described research project. I understand that my participation in this project is voluntary, that I am free to withdraw from participation at any time, and that my choice of whether or not to participate in this project will not jeopardize my relationship with the Department of Social and Health Services or the Developmental Disabilities Council.

I have read, understood and agree to the foregoing.

Participant's or Guardian's Name: [Print Name] \_\_\_\_\_

Participant's or Guardian's Signature \_\_\_\_\_

Date: \_\_\_\_\_

If you require reasonable accommodation please describe your specific needs:

\_\_\_\_\_

Please contact the host facility by: [Date]

## Focus Group Protocol

- Three groups; 2 groups with SSP-eligible individuals with developmental disabilities in transition/employment programs, and one group of individuals with developmental disabilities receiving residential services.
- We will work with counties/service providers to arrange, host and coordinate the meetings. All initial contacts with the participants will be accomplished via case managers or service providers. Group sessions will be held at a provider or county facility.
- Assume 8-10 participants per group.
- The group discussion will last no more than 1 1/2 hours.
- will also be provided to defray costs of participation. Refreshments will also be provided.
- The goal is to maximize diversity of participants.
- Language barriers will be addressed by providing signing and translating services as available by the host.
- Groups will be tape-recorded (tapes will be transcribed).
- Participants/guardians will sign an informed/consent agreement. We do not expect the experience of participating in these groups will harm participants in any way.
- The groups are being held to ascertain their views/experiences of the SSP change over a two year period.
- All groups will be facilitated by two trained facilitators, assisted by a person with DD experience.

## Focus Group Discussion Guidelines

1) Introductions - tell us about yourself

2) Tell us about your experiences with SSP

Probes:

- self determination
- handling money
- complexity (paperwork)
- access to services/choices
- information about SSP changes
- impacts on other means-tested programs

3) How are your relationships with your case workers and providers changed (or not?)

Probes:

- complexity (paperwork)
- access to services/choices
- information about SSP changes

4) What is good about the SSP changes

Probes:

- self determination
- handling money
- access to services/choices

5) What is bad about the SSP changes

Probes:

- handling money
- complexity (paperwork)
- access to services/choices
- information about SSP changes
- impacts on other means-tested programs

6) What would you do differently with the SSP, if anything?

## APPENDIX E: GLOSSARY OF TERMS

Case Manager	A person responsible for planning, coordinating and implementing a person's Individual Program Plan (IPP).
County DD Staff	County employees whose job it is to administer employment and day services in the counties for individuals with developmental disabilities.
Developmental Disability	A disability that is acquired during the period the person is developing, generally before age 21 or at birth, and that significantly impacts several life activity areas such as self-care, self-direction, learning, mobility, speech, and independent living.
Employment/Day Program	Employment/Day programs serve individuals who have a major life goal of finding work for the purposes of increasing financial security, personal fulfillment and meaningful participation in their community. These programs provide training and placement in employment, matching jobs to people for the benefit of client and the community.
Families/Guardians	A person or agency that assumes limited or unlimited authority to make decisions for a minor or an adult who has been determined to be incompetent in a court of law. Includes medical guardianships, guardianship of the person, and guardian of the estate.
Family Support Program	A program designed to offer supportive services for families/guardians who have children with special needs and live at home.
Individuals with Developmental Disabilities	A person with living with developmental disabilities.
Maintenance of Effort (MOE)	A stipulation requiring states to maintain certain in-state funding (levels for programs in order to continue to receive federal funds for similar programs.
Representative Payee	A person or organization that is authorized to cash and manage public assistance checks (SSI, SSP, etc.) for a person deemed incapable of doing so.

Residential Program	This service is provided to individuals with developmental disabilities who do not live in a family/guardian residential setting. The service provides assistance and skills related to activities of daily living, such as, personal grooming and cleanliness, bed making and household chores, eating and the preparation of food, and the social and adaptive skills necessary to enable the individual to reside in a non-institutional setting.
Self-Determination	The ability to take control and assume responsibility for one's life by making choices and decisions based upon personal interests, abilities and preferences.
Service Provider	An individual or any publicly or privately operated program, organization or business providing service or supports for persons with developmental disabilities.
SSI	An income support payment administered by the Social Security Administration provided to children with disabilities and adults who are disabled, and whose income and assets fall below a prescribed level after accounting for Social Security work incentives.
SSP	State Supplementary Payment
SSP Recipients	Individuals with developmental disabilities or their families/guardians who receive SSP benefits.
Supports	Any one of a number of accommodations, persons in the environment, or practices that help an individual in conducting life activities, including employment. Examples are: Family support programs, respite care, professional therapies, transportation, residential services, parent/family counseling, environmental modifications, training, and employment/day services, etc.
Title XIX-Medicaid	Federal program that provides Medicaid funding for state programs and services offered to persons with developmental disabilities.
Vendor	A person or organization approved and paid to provide services to people with disabilities.



Voluntary Placement Program

Voluntary Placement Programs provide a range of services to individuals with developmental disabilities, including:

Basic maintenance (e.g., room and board, clothing, and personal incidentals), specialized support (for children with exceptionally and highly individualized needs), respite care and childcare, professional services (e.g., counseling, evaluation, physical therapy, nursing, and medical and dental), and other services (e.g., transportation and community activities)

**Self-determination as defined by Public Law 106.402 Section 102 (27):**

**SELF-DETERMINATION ACTIVITIES** - The term 'self-determination activities' means activities that result in individuals with developmental disabilities, with appropriate assistance, having –

- (A) the ability and opportunity to communicate and make personal decisions;
- (B) the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individuals receive;
- (C) the authority to control resources to obtain needed services, supports and other assistance;
- (D) opportunities to participate in, and contribute to, their communities; and
- (E) support, including financial support, to advocate for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities.